

## **Review Comments Submitted on the Draft KanCare Amendment**

**Received as of: July 31, 2013**

"I am the 66 year old guardian of a man, my brother, 61, who has cerebral palsy, developmental disabilities, severe chronic depression, and a host of medical problems, and I am adamantly opposed to KanCare, as it now stands, and even more so to expanding it to include Long Term Services and Supports (LTSS) for people like my brother.

When KanCare started paying for medical services, on 1/1/2013, my brother lost his primary care physician, even though the doctor was with the Wichita Clinic, which had contracted with the Managed Care Organization (MCO), Sunflower, that we had chosen! How is that?! Luckily, our fabulous case manager caught the error, and was able to sign my brother up with the doctor whom he has been seeing for 13 years. Whew! (I presume switching people randomly to new doctors is not the method of improving health care the governor had in mind, even though he did ram KanCare down our throats.) This random switching reflects careless indifference (or possibly just incompetence) on the part of the insurance company. Either explanation should make government entities pause before handing more responsibilities over to this MCO. And, unfortunately, I've heard the other MCO's are equally bad, if not worse.

The second change initiated under our MCO was to sever the relationship between my brother and his psycho-therapist. Since she had not contracted with Sunflower, he was unable to continue seeing her. I had thought from information I had received prior to the beginning of KanCare, that clients could arrange to keep their old medical providers, even those who had not contracted with the client's MCO, if the providers agreed to accept less pay from the MCO. My brother's therapist agreed to accept less pay; but the MCO refused to pay her at all. So, I had to find a new psycho-therapist, which I did. Had we kept the old Medicaid system, I would not have had to do this. Moreover, leaving a therapist with whom you have good rapport and who knows you and your condition does not "improve health outcomes," one of the stated goals of KanCare.

It is obvious to me that continuity of care is not a priority with the MCO's, and it may not even be a consideration. This worries me tremendously when thinking about the expansion of KanCare into LTSS for the ID population. My brother is fairly helpless, understandably insecure, and easily confused. Keeping him on an emotional even-keel requires continuity, as it does for almost all people with DD.

To place the day to day living arrangements of this population in the hands of an insurance company which has already given evidence of incompetence and/or indifference is basically criminal behavior. The State has the responsibility for these people's lives, since it is taxpayers' money that pays for the services that keep them alive. This will not change under KanCare. Therefore, the State will be responsible for the chaos about to be set loose by the expansion of this poorly conceived and executed program to include LTSS for the ID community."

**###**

"I find it both funny and sad that so many people are speaking out AGAINST moving I/DD services into KanCare and cutting a program that has been working so well for so long. The funny and sad part is that the people who are electing the people to make these decisions have made their point very loud and

very clear yet, here we are, still telling them same people what we want (and our children who are being supported) and being ignored ... still! We have Secretary Sullivan telling everyone, "KanCare will provide better health, employment and housing opportunities". So, what you are saying is that you (and the people working for you) are not capable of doing your job(s)? In spite of your inability to provide services to those who are supposed to be receiving those services, our local case managers and CDDOs are doing just that...they are providing outstanding services to those in need. Secretary Sullivan goes on to say that "the current system fares poorly in managing chronic conditions ...". Well, these individuals do not suffer from "chronic" conditions. These are lifelong disabilities! These are the very conditions that insurance companies are not qualified to handle. Sure, they deal with individuals that truly do suffer from chronic conditions but, they are medical/health related conditions. The goal for these people is that the long term care will stop within a reasonable amount of time. The people that are supported through the I/DD waivers are people with LIFELONG disabilities ... they will require assistance for their ENTIRE life. Not just a couple of years and get better.

The sickening part ... even though there is the vast majority of people NOT supporting a move to KanCare, it's going to be shoved down our throat because it's good for us. I'm sorry, I disagree! An insurance company is not set up to deal with the needs of these people. They aren't prepared to handle long term services such as meal preparation, job coaching, money management, buying groceries, and other life skills that you and I take for granted. Please tell me how an insurance company is going to provide these services better and more efficiently than our current system. We'll be nothing more than a number to the big insurance company in a totally different state. Yeah, that sounds a whole lot better!

Like the rest of us who have fought this so hard for so long, the CEO of Cottonwood Inc. (Sharon Spratt) summed it up, "I'm resigned that it will be implemented and I guess we are going to have to live with it".

When are you going to listen to the people that elected you to speak for us and act on our behalf?!!"

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"1. Things that were covered but then once the lock in occurred they were taken away as "not a covered service"

I have had multiple clients that picked Amerigroup due to covering depends but then when the lock in occurred Amerigroup stated that it was not a covered service. This was the primary reason they chose that MCO then for families to have to switch the way they get the items and go through the necessary steps to get them covered was a hassle. Then once they were locked in Amerigroup chose not to cover them any longer.

2. Concerns about saving money are affecting the outcomes for people. I have a child on my caseload that is a danger to the community. He is currently on the waiting list for Parson's State Hospital while in placement at a PRTF. We were not able to locate a foster home for him due to the aggression and his violent nature. He cannot go home due to the aggression toward siblings and parents. The MCO is wanting him out "no if, ands or buts." What happens if they send him back into the community? He is going to hurt someone. His Psychologist, staffing provider, the local police and all involved in his case have stated that the PRTF is the best placement for him until a bed opens in Parsons. But due to the high cost of the PRTF they are wanting him out. We have been able to keep him in a month longer than they wanted due to the child was moved to the top of the waiting list at Parsons but after the call this morning it appears they want to send him into the community. He has an IQ of around 40 which makes him a target to older more aggressive kids so Bob Johnsons or another JJA facility is NOT the appropriate placement for him.

3. I have been told multiple times that the Care Coordinators have caseloads of over 100. In some cases 200. How do you expect the Care Coordinators to stay current on assessments and provide quality care coordination when they have caseloads that high? They can't! They are behind, in some cases, by months and then people are losing services or not receiving adequate services because the MCO's do not understand the other waivers. Those waivers are all more medical and have more in common with each other than the IDD Waiver. I have worked on multiple waivers and have some understanding of each one so I can attest that they are very different than the IDD waiver.
4. A medical model is not appropriate for IDD long term care services. This is not an illness, they cannot be healed. These are long term care supports that people will need for a lifetime.
5. We have not had a pilot program start, let alone be successful, yet the State is trying to lead people to believe that it has been in process and meeting objectives. I don't understand how they can say that when nothing has been done yet.
6. It is taking more time and money to call the MCO's and try to get in touch with someone's care coordinator. You get the run around, get hung up on and people do not even know who is the care coordinator. Then when you do finally get somewhere, they don't call you back or give misinformation that leads you on another wild goose chase.

Thank you for your time"

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"According to the paper, Mr. Shawn Sullivan said that only 10% of those with developmental disabilities in KS, receiving assistance are employed. I don't think that fact is true. Many are employed in the Cottonwood workshops and Cottonwood also has Job Link where people are found jobs in the community. Normal people are having trouble finding jobs , much less the mentally handicapped ones, with fewer job skills, whose attention span is less. Their jobs are dependent on the social acceptance of the employer for their slowness, or inability to do ALL the tasks , where "job carving" has to be done, where job coaches are needed, etc. How is the new "plan" going to provide new opportunities for these people to work? KS does not have the opportunities that other states have in the cities employing people with disabilities. It is more agriculture.

My son had a small job at a firm of Westheffer and he shredded paper, but then the recession came and he lost his job, just like the "normal" ones did. They did cut backs. So, is the new "plan" going to provide workshops, find jobs for the developmentally challenged, and have a job coach, or case manager, for these people , in case they have issues? If it doesn't work as planned are we the parents of the disabled allowed to go back to this plan?

Send information about the other states employment whom you boast of having a higher job rating for the disabled and IF they have any tips that we should know about."

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"I am a parent of a person with DD and a representative of other families in Johnson County. In this brief email testimony, I do not have the opportunity to touch on the many points that Secretary Sullivan mentioned with which we heartily disagree.

KDADS is putting a spin on this radical change in service delivery that does not meet with our experiences. There is no good reason to dismantle the current system in Kansas, which is lean and highly effective. We parents are not dumb; we have studied the proposed change carefully and have concluded that the only way a for-profit insurance company is going to make a profit on serving our kids

is by reducing care. Those people who want to work in the community are doing so already. In nearly all counties of Kansas we are offered a choice of service providers, and we prefer to interact locally with them in managing the daily services for our folk.

We are not opposed to including our people into the medical portion of KanCare. But our kids are not sick; they are not “patients” as our Lieutenant Governor continues to call them. They are fragile individuals whose daily care is best served under the present delivery system, not an out-of-town company with no expertise in serving our kids daily needs.

We do not want to be carved into KanCare for the behavioral and daily needs of our children.”

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“This should come as no shock to you. I am the parent and legal guardian of a 23-year-old Kansas citizen, Megan Elizabeth Holtz, who receives full-time living support through the HCBS waiver, and I am strongly opposed to including long-term I/DD services in the KanCare program. I, along with almost all of the families I am aware of of special-needs Kansans, have tried in every way we know how to make our opposition known for the last 18 to 24 months. So far our concerns have been totally ignored by a state administration which, for reasons mysterious to me, is hell-bent on entrusting these critically important services to three private managed care companies.

I want it to be clear that I did not oppose, and do not now oppose, using these companies to manage the health-care (Medicaid) services the state provides to my daughter. Health care services, designed to promote wellness and identify the most effective ways of treating illnesses, are what managed care companies are good at, what they have the knowledge and skill bases to manage. Although there have been problems and concerns with the transition to the medical services portion of KanCare, I accept that it is a reasonable way of going, with the potential to save the state's taxpayers money.

But long-term I/DD services are NOT healthcare! With very rare exceptions, the recipients of these services do not “get well,” but need the services for life--so many of the managed care evaluation tools are useless when applied to these services. When pressed to tell us how the inclusion of long-term I/DD services saves the state money without reducing services, the state administration almost always falls back to talking about health care issues (e.g. we can get the person diabetes screens), which can be done without carving in I/DD services. The current system of providing these services serves my daughter well, has most of the “kinks” already worked out because it has been in place for many years, and is particularly valuable to citizens like my daughter for whom stability in the people she works with is a highly important matter. In two years of trying, KanCare advocates have yet to come up with a compelling rationale about why putting these services into KanCare will in any meaningful way benefit my daughter. Instead we have had ham-handed threats to punish Kansans on the special services waiting list (which is a disgrace to our state, but that's a different conversation) if I/DD services are NOT included in KanCare, and patronizing reminders that “change is always hard,” as though that self-evident truth automatically means that all change is for the better and we're just too dumb to realize that.

So I would appeal to the Centers for Medicaid & Medicare Services to refuse to grant the waiver which the state apparently requires in order to move I/DD services into KanCare. The fact that despite overwhelming political pressure from the administration, and a veto-proof ultra-conservative majority in the Kansas House, the vote to keep I/DD services out of KanCare was initially tied (before a few legislators could be persuaded to change their votes) ought to indicate that there are serious

reservations, even among the administration's ideological allies, about the wisdom of this step. Approve a small-scale pilot program if you must, let families who are willing (if you can find them) try this for five or ten years (these are long-term services, remember), and then if it genuinely proves to be a better way to go, come and share the stories and the documentation with us. But please, do not now, with no certainty that there is benefit either to the state or to Kansas citizens like my daughter, throw the future care of thousands of citizens with special needs into doubt in this untested approach.

Thank you for the opportunity to express my views.”

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“Turning the IDD community support over to private insurance companies is insane. They have no experience in this arena. They are driven by the need to make a profit. Their first concern is to their shareholders.

Pilot program has not been completed and the state of Kansas has not completed the cost/benefit analysis to justify this approach.

SHOW US THE STUDY THAT JUSTIFIES TURNING OVER IDD SERVICES TO PRIVATE INSURANCE COMPANIES”

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“There are significant and widespread concerns regarding the implementation of KanCare for Kansans with intellectual and developmental disabilities. There was a noticeable lack of inclusiveness in the development process of the 1115 Concept Paper submitted by the Brownback Administration, as well as the overall development of the KanCare managed care proposal. While the Administration points to a series of “public forums” held during the summer of 2011 as public input opportunities, the vast majority of Kansas parents of children with I/DD were not aware of these discussions and only found out about the inclusion of longterm care for their loved ones in KanCare after the Administration’s Request for Proposal was released to potential bidders and the public in November 2011. Even the advocates who had met with the Administration on this issue had been kept in the dark as to the inclusion of I/DD longterm care services until after release of the RFP. Concern is widespread regarding the lack of a voice and a stake in the planning process for KanCare.

There is an unsettling absence of stated outcomes for the Kansas I/DD population within the Brownback Administration’s KanCare proposal that would lead to an improved quality of life for these Kansans.

Further, the very few number of states nationally that have included non-medical long-term care for the I/DD population in their Medicaid managed care plans cannot provide demonstrable outcomes indicating an improved quality of life for this population. This leaves me with great concern that the Brownback Administration will unnecessarily expose Kansans with I/DD to needless change, which may have serious negative impacts on the quality of their supports.

The types of sweeping system changes embodied in the Brownback Administration’s KanCare managed care proposal cause great concern regarding the vulnerabilities of Kansas I/DD population. I am particularly concerned regarding changes that may occur in the medication management of these individuals that could “de-stabilize” them and lead to costly hospitalizations for resulting behaviors. I,

along with many other caring citizens sent emails and letters to the Brownback Administration urging that that KanCare receive greater examination before implementation, and also expressing concern regarding the lack of any significant incorporation of input from families of Kansans with developmental disabilities. Unfortunately, our concerns have largely been dismissed by the Administration.

I will be a willing partner in discussing potential ways to improve the Kansas DD service system. However, we urge that these changes be planned and implemented in a thoughtful way in order to shield Kansans with intellectual and developmental disabilities from as many unintended consequences as possible.

I do not believe that the extremely fast pace that the Administration has chosen in implementing KanCare meets that requirement. Therefore, I would request that CMS provide significant scrutiny of any proposal to carve in I/DD service submitted by the State of Kansas."

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"I attended the public comment meeting today. I totally feel for those families that spoke. Please do not change a system that has been working for them. I can't imagine the emotions, fears and heartache that come with taking care of their children. Please don't add problems of dealing with their coverage and service providers. If you want to do pilot, do a survey with the families of those 8000+ you serve to ask if change is needed and go with the majority. Please don't try to use data to make those changes. Data didn't truly represent what the families are going through. Say no to carve in."

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"Kansas has not done due diligence on the subject. In their haste they have caused tremendous trepidation among its consumers and their parents and gardens. Please do not let this haste cause waste of this wonderful program.  
Do not give approval."

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"I am very concerned about the carve in of I/DD Services into Kancare. There is no mechanism for billing the I/DD services at this point yet we are supposed to be participating in a pilot. UHC is pointing the finger at the state for the lack of billing development. What is being done to rectify this problem and how can this start on January 2014 when the pilot is lacking all the components needed to fully participate?"

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"We would like to express our concern that the public is being told the transition to KanCare was going quite smoothly. First of all, choosing a company from three options is something other insured patients in Kansas do NOT do. That choice was most confusing to the patients and it added three new insurance companies rules, contracting, processing to most physician offices and hospitals. This is a waste. Some offices choose to contract with one or two insurance companies and the KanCare system still assigned that physician's established patients to the third company. The database of existing 2012 Medicaid patients did not seem to be used to help patients make good decisions concerning

continuation of care. We recently found our list of patients included many patients we did not even know and did not include patients who should have remained on the list. The process would have been difficult for any Kansas resident let alone some of our most needy residents. ( The third item detailed in the First Quarter Report reflected database problems also, which affected disabled persons. ) The amount of time providers have spent working this transition of healthcare in Kansas, which is unreimbursed, is staggering and has not been addressed or appreciated. Thankfully most physicians are still willing to care for the KanCare population without decisions being driven by financial gain. That fact alone is why KanCare is functioning in its second quarter.”

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“The Kansas Association of Centers for Independent Living (KLACIL) respectfully submits the following testimony regarding the first six months of KanCare.

1. KAICL is pleased to report that as of June 2013, HCBS waiver plans of care are not being reduced in general and some are being increased as needed.
2. Secretary Sullivan asked for FMS providers to continue providing payroll services without authorizations. CIL’s complied and now some are having difficulties getting paid.
3. Payment grievances require in person attendance for the hearing this is very expensive and time consuming.
4. FMS providers are still experiencing extremely lengthy periods of time to receive change of service notifications.
5. Care coordinators need additional training especially on TBI Therapeutic Services, such as Transition Living Specialist.
6. Over payment paperwork and the requirement of sending a paper check is an enormous administrative burden.
7. Families assisting their waiver family members report the KanCare process if very hard to understand and navigate.
8. All three MCO’s are more accessible to member CILS and communication is improving.

KACIL offers to provide Independent Living Philosophy, Core Services, Self-Direction, and Transition Living Specialist trainings to Amerigroup, Sunflower, and United Health Care.”

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“I don’t believe that any of the three KanCare MCO’s was sufficiently prepared to take on the challenges of the Kansas Medicaid Program. We, as providers, have been made to endure huge delays in payments, not having our providers set up accurately in their system, incorrect payments on RHC vs Fee for Service claims, etc.

On top of that, we are told that the KanCare products do not have to pay us interest on any clean claim that is not paid by them within the 30 day time frame that is mandated for all other carriers practicing in Kansas.

The State needs to reflect on their time frames when making this type of transition and give all parties ample time and opportunity to test systems to insure all involved are adequately prepared and that provider reimbursement is not jeopardized.”

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“Problems that we are continuing to have with the Kan Care MCO’s:

Our providers are not listed on the websites. (or incorrectly listed)

Incorrect payments for RHC’s – ie: we have two RHC’s (two completely separate physical locations and addresses) – we are being paid two different encounter rates (which is correct), however MCO’s have comingled the reimbursement on the same remittance advice.

No payment on claims –when calling in to inquire why – after 30 minutes being told “I see no reason for non-payment, we will reprocess”. MULTIPLE non payments on several RA’s.

A nonpayment on an RA, inquiry and being told provider is not in the network – even though we were correctly paid for the same provider on the same RA.

Little or no contact with provider reps. Get voice mail or auto responses from emails.

These above situations have caused a great deal of man hours and effort for our practice. This is extremely frustrating and exhausting to work through.

Thank you for this opportunity to comment on the implementation issues surrounding KanCare. Our comments are collected from dialysis social workers across Kansas who provide services for dialysis patients in our 24 outpatient dialysis facilities. Our comments focus on issues that are directly impacting Medicaid beneficiaries including transportation, complexity of processes, prior authorization, and arranging payment coverage for dialyzing at other facilities during times of travel.

#### Transportation Coverage:

Prior to KanCare, the contracted transportation providers would provide services for people who were private pay and did not have Medicaid. Now, our social workers are being told that the transportation providers’ contracts state they can only provide transportation for Medicaid beneficiaries. This has caused great problems for dialysis patients who are not on Medicaid and have now lost what can be in some rural areas their only source of transportation to life-sustaining dialysis treatments three times a week.

A second transportation issue is related to transportation providers that are not allowed to cross county lines. We have some dialysis patients who live in one county but receive their outpatient dialysis in a different county and are not able to find transportation due to the providers not crossing county lines.

Third, we understand that ideally dialysis patients should arrange their own transportation. However, some patients are elderly, frail, or for other reasons are not able to arrange their own transportation. It would be helpful if the transportation providers would allow social workers or other staff to call and assist with coordinating transportation needs.

#### Prior Authorizations:

There are several issues related to prior authorizations. First, patients are not always able to call and request their own prior authorization. Similar to the transportation issue, it would be helpful if the KanCare plans would allow social workers or other staff to call and assist with coordinating transportation needs.



When a dialysis patient has problems with his or her vascular access, they are required to have a prior authorization to receive a dialysis treatment at the vascular access facility. The KanCare plans state they want 5 days' notice if possible. This is not realistic as the issue with vascular access is an urgent issue, and patients need dialysis the same day or the day after they discover problems with their vascular accesses and require interventions and treatment at the vascular access facility.

#### Arranging Travel:

Dialysis patients occasionally wish to dialyze at a different facility due to travel. KanCare plans are requiring complicated processes that patients are finding difficult to follow through with or suggesting that patients use the internet or smart phones to arrange their travel which can be intimidating for some patients who do not use this type of technology. Either the process needs to be simplified or the dialysis staff need to be involved to assist patients with the required KanCare needs for approving payment for dialysis received at other outpatient facilities.

Thank you again for this opportunity to comment.”

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“InterHab represents 43 community service providers and community developmental disability organizations throughout the State of Kansas. Our association has been a part of collaborative efforts to review the planning and development of KanCare with consumer and family advocates and the Federal I/DD network (Disability Rights Center, Families Together, Kansas Council on Developmental Disabilities, and the University of Kansas Center on Intellectual and Development Disabilities).

The following comments are submitted to register InterHab's objections to our state's proposal to CMS to amend the Kansas 1115 waiver to fully incorporate HCBS long term services and supports for persons with I/DD into the state's Medicaid managed care program known as KanCare.

It is the recommendation of InterHab, based upon feedback received from stakeholders and our members, that CMS should not approve the State's proposal to incorporate the I/DD HCBS waiver services into the State's managed care program (KanCare).

We have supported KanCare's concepts to coordinate physical and behavioral health services, but few of those concepts are transferable to the work of the I/DD/LTSS home and community based programs, which long ago demonstrated that savings and improved outcomes could be gained by moving away from the medical model which dominated the management of all Medicaid programs prior to the adoption of HCBS as a program option.

The reasons to reverse the current and historic success experienced by persons with I/DD and to incorporate long term supports and services into KanCare have still not been well established. There is little useful research which might have guided how best to implement such a proposal, due to the lack of national models to examine, and the resulting plans are therefore long on experimentation and speculation, but lacking in the lessons of practical experience and professional expertise.

The proposal that KanCare should include I/DD LTSS reflects a first step in what would become a dangerous trend to reverse the most positive financing policies to have ever impacted the lives of persons with I/DD, i.e. the creation of the HCBS waiver option for LTSS for persons with I/DD.

History reminds us that the creation of the HCBS waiver was to allow for a more efficient use of Medicaid dollars for its non-medical long term services and supports. HCBS was and is enormously successful, in opening the doors to our society for tens of thousands of Americans who previously could only receive assistance in state and private institutions.

The late 1980's shift in policy which brought the current LTSS environment was this:

That Medicaid programs which were largely designed and utilized by health care professionals were inappropriate for the long term needs of persons with I/DD. The so-called "medical model" subordinated the lives of person to the system that served them. HCBS shifted from facility financing to person-centered financing. HCBS in effect was the first carve-out of I/DD LTSS, to assure that each person's life could be treated as a "life", and not as a component of an actuarially-based health care financing program. HCBS policies were premised on the recognition that person-centered LTSS could not be effectively or efficiently delivered in settings designed to meet the needs of a funding stream which funded facilities, not persons. The move to HCBS financing reduced costs per person for LTSS, maintained closer family relationships, increased integration into communities, allowed for more lives to be more competently and productively lived. The Federal and State governments have saved money in the HCBS model.

The plans for KanCare reverse the positive trends of HCBS, and place I/DD LTSS back into a managed care health plan designed not to enhance or improve LTSS, but to better manage, and thereby reduce the cost of, Medicaid-financed health care. Once again, after decades of progress, we will boldly march backwards into the past, when persons needing LTSS needs were enrolled in a health insurance plan within which their needs were never effectively considered and, as a result, not understood.

Finally, it is important to note that the design of KanCare discriminates against persons with I/DD, and places at financial risk service providers for whom the I/DD population is their sole customer base. Among all Medicaid beneficiary groups, none will feel a fraction of the impact that persons with I/DD will feel. The incorporation of all medical services into KanCare will cause similar impacts to all groups of persons who are Medicaid beneficiaries. However, the person with I/DD receiving LTSS supports under KanCare will have not only their health care services managed and governed by KanCare, but every moment of their lives as well, awake or asleep.

The nature of the current Kansas model is that the largest share of costs to reimburse for services are bundled and reimbursed under two program components: residential habilitation and day habilitation. Essentially, these staffed services enable persons with I/DD to be able to live, work and develop greater independent living skills. The lives of no other group of Medicaid beneficiaries will be subjected to this level of management for every aspect of every minute of every day of their lives.

To assume that a managed care insurance company can effectively manage a program of this scope, and can or should have the authority to do so, exaggerates their capacity and de-values the lives of each individual subjected to such a program. It is wrong, and it is unfair to subject persons with I/DD to this level of intrusiveness.

In the event that CMS decides to allow the carve-in of I/DD LTSS into KanCare, there must be a requirement that the pilot program currently under development be given time to become completely operational and thoroughly evaluated before the full inclusion of I/DD LTSS into KanCare.

The pilot (in the State's amendment document) is portrayed as well underway, but that statement is at odds with the on-the-ground reality we have seen. Even members of pilot advisory committee would dispute that the program is fully operational. The State deserves positive marks for their work with

stakeholders and managed care contractors to formulate how the pilot might be designed, but many design questions remain, and the pilot will not be fully operational for many weeks, even months. That is not a criticism of the State's capacity to develop a pilot, it simply observes that the sweeping changes which would be attempted by the pilot have not been finalized, and cannot be implemented, tested nor adequately evaluated in such a short time frame.

The amendment to carve-in I/DD LTSS at a minimum should not be adopted until the State completes a fully operational pilot over a sufficient time period to allow an ample test period, and a comprehensive evaluation. In our opinion that cannot be accomplished within the time frame proposed by the State."

###

"I believe that public comment is appropriate, so I am writing.

I am very concerned. I work with developmentally disabled people as a direct support professional. The experimental nature of the new program bothers me. These are people, not guinea pigs. The care that is being proposed does not have much of a track record.

The fact that this measure is being implemented for cost-savings, and not as a way to improve the lives of disabled citizens, immediately shows me that our state government considers disabled human beings to be less valuable than dollars.

The fact that it is developmentally disabled citizens who are being asked to make such drastic changes suggests to me that, since they are the least able to speak up for themselves, they are the most likely to be bullied. Yes, bullied!

Playground politics are at work here.

The system that is in place has been developed over decades. By removing it suddenly, these people will have their lives disrupted to an extreme degree. Who will speak for them? Who can they go to be sure that they are getting the care they need?

By removing case managers and advocates, it will be harder for the system to be responsive. In this scenario, small problems will easily become big problems. Then the big problems will need costly solutions!

These citizens really do need to have high-quality, community-oriented care. By not providing it, not only will the lives of these people become less independent, their needs will increase. Hospitals and nursing homes are likely to become overloaded. By allowing crises to develop, greater care will be needed, and there will actually be no cost savings.

We should not forget the horrific conditions that were allowed to exist at a privately owned turkey farm in Iowa. A jury awarded the abused disabled workers 240 million dollars. Did this save money? It is possible that some may want to return to the days of institutional care, a terrible option. This would be a step backward for our state

Although they aren't saying it, my impression is that some politicians just want the disabled population to die off.

Of all the things that our governor has done, providing “cheap” care for disabled people, and putting their well-being at risk, angers me the most.

The arrogance, and insensitivity shown by Mr. Brownback are no more clearly demonstrated than in this plan to save a few bucks by removing support from developmentally disabled people.”

###

“Thank you for this opportunity to provide comments on the draft Amendment to the KanCare Medicaid Section 1115 Demonstration, 11-W-00283/7.

We have significant concerns about the impact that the waiver amendment’s proposed changes could have for vulnerable Kansans. We believe that neither the waiver amendment in written form nor the two public forums hosted by the state of Kansas provided adequate detail to inform the public about how the state of Kansas developed these proposals, or what the state hopes to achieve. We also question whether the stated objectives of the proposed changes are aligned with the overall objectives of the Medicaid program.

Section 1115 of the Social Security Act gives the HHS Secretary the authority “to approve experimental, pilot, or demonstration projects that promote the objectives of the Medicaid and CHIP programs.” The purpose of the demonstrations is to improve programs through initiatives such as “expanding eligibility to individuals who are not otherwise Medicaid or CHIP eligible” and “providing services not typically covered by Medicaid.”

However, it is unclear how the proposed changes in the waiver amendment would improve programs or services within the Medicaid system in Kansas.

Section A of the waiver amendment requests CMS approval to “no longer carve out” specialized services such as LTSS for Kansans with intellectual and developmental disabilities. According to the waiver amendment, the “state believes that including these 2 services in KanCare will result in better services and improved quality of care for KanCare enrollees.” Yet the waiver amendment does not explain how the state developed this approach and whether or not a similar model has been successfully used in other states. We question how including these services in KanCare would improve the Medicaid program in Kansas, or improve services for KanCare enrollees who require those specialized services. Section B of the waiver amendment proposes three pilot programs which according to the draft amendment are designed to help Kansans transition “from Medicaid to independence.” The sparse language of the waiver amendment provides only limited detail about the Social Security Alternative and SSI Employment Support pilots. For example, the waiver amendment provides little detail to justify whether or not the capped allocation of \$1,500 per month would allow pilot participants to cover meaningful health services. More substantive detail in the waiver amendment and an opportunity to participate in a robust question and answer session during the public forums hosted by the state would have enhanced our understanding of the purpose of these pilots as envisioned by the state and allowed us to more fully comment on the pilots’ implications for vulnerable Kansans. Kansas consumers who do not work for professional advocacy organizations have not been privy to clear explanations of these pilots and are therefore even less equipped to comment on the proposed changes.

The Health Account Pilot in Section B raises significant concerns. An allotment of \$2,000 per year would be spent quickly if an individual participating in the pilot were to have significant health needs. In

addition, the waiver amendment says that individuals who participate in this pilot would “waive their right to Medicaid eligibility for one year after their participation in the pilot ends.” While the waiver amendment does indicate that exceptions would exist for certain qualifying events, this pilot does not offer supports to help the participants seek or sustain meaningful employment that offers insurance coverage. Without a robust support structure in place, the pilot participants could find themselves in a precarious financial and health situation; it is doubtful that the prepaid debit card would cover meaningful health services and if the pilot participants were previously eligible for Medicaid, it is highly unlikely that they have the experience, education, or financial and health literacy necessary to successfully navigate the employment and employer-based insurance landscape.

In addition, we question whether a Medicaid demonstration project is the appropriate vehicle to move Kansans away from the Medicaid program. Is it appropriate to use Medicaid funds to create a situation where Kansans waive their eligibility for the Medicaid program? Is a pilot program that seeks to keep Kansans away from Medicaid in alignment with the purpose of demonstration projects as laid out by the Social Security Act?

We have lingering questions and concerns about the waiver amendment as it has been presented by the state. We hope to receive answers and respectfully ask you to be responsive to our concerns in your ongoing discussions with CMS and Kansas stakeholders. 3

We remain committed to advocating for vulnerable Kansans and ensuring that the Medicaid system in Kansas works for them and their unique needs.”

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“I wish to make the following comments regarding the proposed amendments which were presented at the recent public hearings:

A. Social Security Alternative Pilot.

1. As I understand your description of the program, applicants will be required to waive the right to apply for Supplemental Security Income (SSI) or Social Security Disability benefits (SSD). Waiving the right could cost the applicant thousands of dollars in SSI or SSD benefits if s/he fails to meet the minimum employment levels of the program. If found eligible SSI and SSD applicants are entitled to retroactive benefits for the time they waited for a decision. SSI applicants are entitled to retroactive benefits from the date of his/her application. A SSD applicant’s retroactive benefit start date can predate the application date by up to 12 months.

KDHE staff should be required to fully explain the potential financial consequences so a program applicant can make a fully informed decision whether to participate. At a minimum staff should prepare a written waiver with a full explanation of the consequences of participation and give the applicant adequate opportunity to review the document, including allowing him/her to take it home or contact the Social Security Administration for additional information on its application process.

2. The written waiver should also explain; a) that the PMDT’s determination of medical eligibility for SSI/SSD is not binding on the Social Security Administration if the applicant fails to complete the program and applies for SSI/SSD; and b) that employment obtained through the program may have a negative impact on a later application for SSI/SSD, particularly if a participant who is eligible for SSD has earning exceeding SGA for 9 months.

3. Presumably, an eligible applicant for the program would also be eligible for Vocational Rehabilitation (VR) services. Many may benefit from VR services to enhance his/her employment opportunities, such as education, training, and work transportation costs, just to name a few. Often such plans take months to develop and implement. The program description, however, gives no explanation how or whether KDHE staff will coordinate with VR to provide a full array of services to give the participant the best opportunity to obtain employment.

I believe 6 months is not adequate to give participants an opportunity to obtain and retain employment that will provide adequate income to live. Individuals with disabilities that meet the criteria for SSI/SSD often have medical needs that must be addressed to give them a better opportunity to obtain employment. VR assistance, such as working with employment specialists, on the job training, and trial work periods often last 3 – 6 months. I suggest increasing the trial period from 6 months to at least 12 months to avoid a high dropout rate.”

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“We are the federally designated Developmental Disabilities Network in Kansas. Established by the Developmental Disabilities Assistance and Bill of Rights Act, the Kansas Developmental Disabilities Network consists of the Kansas Council on Developmental Disabilities, the Disability Rights Center of Kansas and Kansas University Center of Excellence in Developmental Disabilities and exists to improve the lives of Kansans with developmental disabilities through capacity building, systems change, advocacy and the enforcement and protection of legal and civil rights. As such, we respectfully submit these comments regarding the proposed amendment to the KanCare section 1115 Demonstration, with the understanding that states are facing increasing caseloads, as well as increasing costs. The Kansas Federal Developmental Disabilities Network, acting in its role of advocating for Kansans with Developmental Disabilities, is on record and remains on record in strong opposition to any managed care arrangement that includes the LTSS of the ID/DD population without substantial and specific piloting and planning of such a transition due to the lack of evidence that these type of managed care arrangements do, in fact, produce better outcomes for those with ID/DD, and can be implemented without inflicting irreparable harm on a well-established mature DD system with years of excellent service delivery history. We also want to stress that the DD Network is already on record stating that KanCare should be successfully piloted first and that it is being implemented at a speed that is dangerous and reckless. Those comments still hold true today. ID/DD inclusion in a managed care model has still not been successfully piloted. The speed of inclusion of ID/DD in the managed care arrangement is still dangerous and reckless. We are hopeful that HHS will hear these concerns from the federal DD Network and take them into thoughtful consideration.

#### Recommendations to strengthen the transition to MLTSS of KanCare for ID/DD Population

1. Long-term Strategic Planning – Prior to moving forward with a transition of ID/DD LTSS to KanCare, it is imperative that Kansas develop an adequate long-term strategic plan to safely and successfully transition the ID/DD population to KanCare. This plan should be developed with the following core principles as its foundation:

- a) Ensuring that Kansas develops a long-term plan to substantially reduce the waiting lists for HCBS Waiver services. One method to do this would be for HHS to place some specificity in a current term and

condition from last year's KanCare application. In the prior terms and conditions document promulgated by HHS, it required that Kansas must dedicate "some" portion of KanCare savings in order to reduce HCBS waiting lists. However, it did not require a specific percentage. We believe that if HHS approves this 1115 Waiver application that HHS should further require in that term and condition that at least 60% of all KanCare savings must be dedicated to reduce HCBS Waiting Lists.

b) Ensuring that people with disabilities are able to live full and healthy lives while participating in their communities as persons without disabilities are able to do.

c) KanCare must be designed to provide for LTSS that are implemented with person-centered principles and allow for consumer choice and self-direction.

d) KanCare beneficiaries with developmental disabilities, who are of working age, should receive adequate supports and services that allow for the attainment and retention of fully integrated and competitive employment.

e) Families must be afforded the necessary assistance to effectively support and advocate for their loved ones.

f) Adequate safeguards must be in place that protect against abuse, neglect and exploitation; and provide for adequate protections during an appeals process to ensure the continuation of services. These safeguards must include an independent ombudsman-type office, similar to the Wisconsin model. Last year HHS asked the state of Kansas to develop a plan to have a true independent Ombudsman. Unfortunately, the state came back with a proposal to have an internal Ombudsman. We believe that HHS should make its support of this new 1115 proposal contingent upon the State of Kansas having an actual external and independent Ombudsman (see later point).

g) A clear and detailed set of quality measures that allows for state and federal oversight and accountability, incentives for MCOs to focus on meeting the expressed needs of ID/DD waiver beneficiaries, tracking of these outcome measures over time, data sets that assists states, MCOs, and providers to effectively evaluate the effectiveness of this type of model across clinical and LTSS settings, is helpful for beneficiaries to make sound choices in plans, and allows advocates and policymakers to identify programs with the best outcomes.

2. Actively seek the assistance of nongovernmental stakeholders in the design and implementation of KanCare for LTSS for the ID/DD population – In the draft amendment for KanCare, dated June 27, 2013, the State of Kansas asserts that "...substantially fewer objections have been raised regarding the inclusion of ID/DD services in KanCare than was the case before KanCare launched in January of 2013." This claim is simply not true; in fact, the objections were substantially more pronounced and vigorous during the 2013 legislative session. Over the course of the past two years, advocates for persons with ID/DD have sought to make recommendations to the State of Kansas regarding the KanCare proposal, but there has been no effort on the part of the state to incorporate any of these recommendations into their proposal. Often times the design and implementation of KanCare has occurred behind closed doors and notification of any pertinent information comes after the fact or in such short notice that it is often times difficult, if not impossible, to react or engage with the state to have an impact on the design or implementation.

3. Independent Advocacy or Ombudsman Program – When Kansas originally submitted its KanCare section 1115 demonstration proposal, advocates strongly urged the State of Kansas and CMS to require the development of an independent advocate or ombudsman program. The state, did not, however move in that direction. In fact, HHS even asked the State of Kansas to develop a plan to create an independent ombudsman. Instead, the State of Kansas opted for an in-house ombudsman program, where the ombudsman serves at the pleasure of the governor and operates more as a traffic cop with no authority to issue tickets. Therefore, this ombudsman clearly does not operate in a “conflict-free” environment to assist KanCare beneficiaries with navigation of the KanCare LTSS landscape, understanding their rights, responsibilities, choices and opportunities, or resolve issues that may arise between the beneficiaries and their MCO. We recommend that CMS require the State of Kansas to provide beneficiaries and their caregivers with an independent ombudsman-type service based on the Wisconsin model. This would give beneficiaries conflict free support and counseling to assist them in understanding their options and do so by means of an independent advocacy or ombudsman program that is not a part of a health plan, state government, community service provider, or any other entity responsible for eligibility determination or service provision.

4. Adequate personnel to manage and effectively administer managed care contracts – Over the course of the past 2-3 years, Kansas has significantly reduced the number of qualified personnel within the divisions of state government that directly manages the provisions of LTSS for persons with ID/DD. The ID/DD HCBS Waiver serves over 8,000 (according to the State of Kansas, Department for Aging and Disability Services). According to the draft amendment, the State of Kansas, will in the first 180 days of 2014, review each MCO’s services planning process. In a case where a reduction of services is deemed appropriate by a MCO, the Kansas Department for Aging and Disability Services will review this decision. The state of Kansas must have an adequate number of staff qualified to review these recommended reductions in services to protect the fragile lives of this population and to protect the continuity of care.

5. Pilot/Opt-Out/ Disenrollment Provisions – With the approval of KanCare, CMS authorized a pilot for the LTSS provision of the ID/DD population that was to take place for DY 1 of the KanCare 1115 demonstration. Unfortunately, this pilot has not yet established any real direct involvement of the MCOs with the ID/DD population, nor has it begun to test a fully integrated, capitated managed care arrangement. Because of the planned shift of some 8,000 plus individuals whom receive LTSS through a FFS arrangement to a fully integrated and capitated managed care system, there is a great deal of concern among advocates, families, providers and individuals themselves regarding the MCOs ability to step in and adequately manage their LTSS. The DD Network of Kansas recommends that CMS require the State of Kansas to provide for an opt-out provision for demonstration year 2 to give the State of Kansas and the 3 contracted MCOs more time to develop a plan to safely transition these individuals to this new managed care arrangement. This will create a natural pilot, as some individuals will not opt-out.

6. Specificity within STCs on earmarked savings – Within the Special Terms and Conditions for KanCare, STC # 46 Earmarked Cost Savings stipulates that the Kansas State Medicaid Agency to “designate a portion of savings achieved through the implementation of KanCare 1115 to increase the number of slots in 1915 (c) waivers to move individuals currently on waiting lists to HCBS. During the 2013 Legislative session, the Kansas Legislature passed a budget with \$18.5 million designated toward waiting list reduction, evenly distributed among the PD and DD waiting lists. However, a budget proviso was added that states... *“Provided, however, That, if services through the home and community based waiver for individuals with developmental*



*disabilities or targeted case management for individuals with developmental disabilities are not provided under KanCare, then on January 1, 2014, of the \$181,695,810 appropriated for the above agency for the fiscal year ending June 30, 2014, by this section from the state general fund in the mental health and retardation services aid and assistance account, the sum of \$4,000,000 is hereby lapsed.”* This budget proviso was approved by Governor Brownback. Families, advocates, providers and all other stakeholders within the DD services system and broader community viewed this as threatening and it certainly has not served well to foster a working relationship between the state and DD stakeholders, but it does reflect the type of strained environment in which we all are required to live and work with. Some feel that this budget proviso, approved by the Governor, is holding the ID/DD Waiting List dollars hostage, in that the Administration is stating that if the inclusion of the ID/DD Waiver is delayed in KanCare that they will not spend the dollars appropriated for Kansas families struggling on the ID/DD waiting list. This is wrong and it goes against the special terms and conditions required by HHS. Those terms and conditions state that a portion of the savings from KanCare must go to reduce waiting lists. They do not make that funding contingent on whether or not the DD Waiver is included in KanCare.

7. Network adequacy/ Statewide Readiness review for MLTSS for ID/DD – For a smooth transition of ID/DD LTSS to KanCare to occur, there must be absolute certainty that there is adequate provider capacity throughout the state of Kansas. This is particularly concerning in the most rural areas of the state. CMS should require the state of Kansas to undergo a statewide readiness review prior to transitioning all ID/DD waiver beneficiaries to KanCare to demonstrate network adequacy among the three (3) contracted MCOs throughout the state.”

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“Kansas Action for Children has reviewed the proposed amendment to the KanCare Section 1115 demonstration and respectfully submits the following comments regarding the impact on children. With regard to Section B(iii), Kansas Action for Children asks for children to be excluded from this pilot opportunity, and that eligible children instead be placed into traditional Medicaid. Language provided in the proposed amendment does not specify whether children will be included in the pilot to provide TransMed beneficiaries with a \$2,000 pre-loaded debit card to purchase qualifying health services or pay health insurance premiums, co-pays, and deductible. If it is the intent of the state to include children in the Health Accounts Pilot, Kansas Action for Children believes the amendment should be changed to exclude children from participation.

Given the complexity of health accounts and the health literacy needed to effectively use health accounts, Kansas Action for Children is concerned that parents of low-income children would not fully understand the potential consequences of forfeiting Medicaid coverage. For children in particular, this would eliminate the guarantee of EPSDT coverage, a central tenant of Medicaid’s coverage for children. Additionally, Kansas Action for Children believes it is highly unlikely that \$2,000 would be sufficient to cover premiums, deductibles and other cost-sharing. Just one broken arm or tonsil-removing surgery would cause out-of-pocket costs to exceed this amount.

For the reasons stated above, Kansas Action for Children believes that children should not be diverted away from traditional Medicaid into a pilot program and we urge the state to exclude children from the Health Accounts Pilot.”

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